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AMENDMENTS TO LB 721

1                   1. Strike the original sections and insert the following  
2 new sections:

3                   "Section 1. Section 81-649, Reissue Revised Statutes of  
4 Nebraska, is amended to read:

5                   81-649. Sections 81-642 to 81-650 shall not be deemed to  
6 compel any individual to submit to any medical examination or  
7 supervision by the department, any of its authorized  
8 representatives, or an approved researcher. No person who seeks  
9 information or obtains registry data pursuant to such sections or  
10 sections 81-663 to 81-675 shall contact a patient on the registry  
11 or such patient's family ~~without first obtaining the permission of~~  
12 ~~a physician actively involved in the care of such patient unless~~  
13 the registry has first obtained the permission of such patient or  
14 patient's family. The registry shall coordinate its activities  
15 with the person desiring such contact and may authorize the person  
16 desiring such contact to perform these contacts under the direction  
17 of the registry.

18                  Sec. 2. Section 81-666, Reissue Revised Statutes of  
19 Nebraska, is amended to read:

20                  81-666. The department may approve an individual or  
21 entity to be an approved researcher upon application and proof  
22 satisfactory to the department that the applicant is a qualified  
23 researcher, that the data will be used for bona fide scientific or  
24 medical research for prevention, cure, or control of certain

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1 diseases or injuries, and that the applicant will maintain the  
2 confidentiality and security of data obtained. The application  
3 shall contain, but not be limited to, the following information:

4 (1) The qualifications of the applicant and of the  
5 principal investigator, if other than the applicant, including  
6 education, experience, prior publications, and recommendations of  
7 professional colleagues who have knowledge and experience of  
8 scientific or medical research;

9 (2) The purpose of the research project, a summary of the  
10 project, and the anticipated time of completion of such project;

11 (3) The location where the research project will be  
12 conducted and the equipment, personnel, and other resources  
13 available to the applicant to carry out the project;

14 (4) The identity of the individual or entity funding the  
15 research project, a description of the availability of funds for  
16 the research project, and any conditions on the receipt or  
17 continuation of such funding;

18 (5) The specific data requested and a description of the  
19 use to be made of such data and, if patient-identifying data is  
20 requested, a substantiation of the need for access to such  
21 patient-identifying data;

22 (6) A description of the measures to be taken to secure  
23 the data and maintain the confidentiality of such data during the  
24 research project, for disposal of the data upon completion of the  
25 study, and to assure that the results of the study will not divulge  
26 or make public information that will disclose the identity of any  
27 individual patient;

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1           (7) If contact with a patient or patient's family is  
2 planned or expected, substantiation of the need for such contact  
3 and a description of the method to be used to obtain permission  
4 from ~~the patient's physician~~ such patient or patient's family for  
5 such contact; and

6           (8) Such additional information as the department  
7 determines to be necessary to assure that release of data to the  
8 applicant is appropriate and will further the purpose of sections  
9 81-663 to 81-675 or the laws governing the specific registry.

10           Sec. 3. Section 81-673, Reissue Revised Statutes of  
11 Nebraska, is amended to read:

12           81-673. Nothing in sections 81-663 to 81-675 shall be  
13 deemed to compel any individual to submit to any medical  
14 examination or supervision by the department, any of its authorized  
15 representatives, or an approved researcher. No person who seeks  
16 information or obtains registry data pursuant to such sections  
17 shall contact a patient on the registry or such patient's family  
18 ~~without first obtaining the permission of a physician actively~~  
19 ~~involved in the care of such patient~~ unless the registry has first  
20 obtained the permission of such patient or patient's family. The  
21 registry shall coordinate its activities with the person desiring  
22 such contact and may authorize the person desiring such contact to  
23 perform these contacts under the direction of the registry.

24           Sec. 4. Section 81-6,105, Revised Statutes Supplement,  
25 2001, is amended to read:

26           81-6,105. Nothing in the Parkinson's Disease Registry  
27 Act shall be deemed to compel any individual to submit to any

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1 medical examination or supervision by the department, any of its  
2 authorized representatives, or an approved researcher. No person  
3 who seeks information or obtains registry data pursuant to the act  
4 shall contact a patient on the registry or such patient's family  
5 ~~without first obtaining the permission of a physician actively~~  
6 ~~involved in the care of such patient~~ unless the registry has first  
7 obtained the permission of such patient or patient's family. The  
8 registry shall coordinate its activities with the person desiring  
9 such contact and may authorize the person desiring such contact to  
10 perform these contacts under the direction of the registry.

11 Sec. 5. Original sections 81-649, 81-666, and 81-673,  
12 Reissue Revised Statutes of Nebraska, and section 81-6,105, Revised  
13 Statutes Supplement, 2001, are repealed."